ORIGINAL ARTICLE

# Adherence of Finnish people with glaucoma to treatment plans and connected factors

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## ABSTRACT

**Objectives.** The aim of the study was to describe the adherence of Finnish people with glaucoma to prescribed treatment plans, the factors connected to adherence and to produce knowledge for developing effective interventions to improve adherence to treatment plans.
**Study design.** This was a cross-sectional study.
**Methods.** The data (n=249) were collected at one point in time from Finnish adults diagnosed with glaucoma with a questionnaire covering adherence to treatment. These patients used glaucoma medication and had follow-up appointments with ophthalmologists.
**Results.** Sixty-seven percent (n=166) of the patients with glaucoma were very adherent to the prescribed treatment plan in terms of self-care, treatment and follow-up visits. Almost all were very adherent to medical care (97%, n=242). More than half of those who had received information from physicians and nurses were very adherent to treatment (66%, n=163). Two factors, support from physicians and nurses ($p<0.001$) and being informed of the consequences of treatments ($p=0.003$), had a statistically significant connection to treatment adherence.
**Conclusions.** This study indicates that people with glaucoma in Finland adhere well to care and exceptionally well to medical care. Support and patient education from health care personnel is crucial to maintain patient adherence to treatment. These results indicate that nurses play a very important role in patient education and support. In practice, it is crucial to maintain this level of patient engagement by developing more tailored and time-saving education and support methods. The results of this study could be helpful for developing new patient education and support approaches for people with glaucoma.
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**Keywords:** adherence, glaucoma, medical care, patient education, support

## INTRODUCTION

Glaucoma is a chronic ophthalmic illness. It is a progressive neuropathy of the optic nerve which results in typical structural and functional abnormalities in the visual field. One of its symptoms is increased intra-ocular pressure. In the majority of the cases, abnormalities progress slowly and occur at the initial stages of the illness (1). The treatment of glaucoma comprises medication, laser treatment and surgical procedures (2). The aim of the treatment is to prevent visual impairment by lowering the intra-ocular pressure. The initial treatment is usually eyedrops. People with glaucoma should visit their ophthalmologist every 6–12 months (3)

For people with glaucoma, fear of vision loss is very common; one-third of patients with glaucoma in Norway were afraid of vision loss, and 80% had some negative feelings during the early stages of their illness (4). Almost half (25–43%) had suffered side effects from prescribed medication(4–6), such as allergic reactions, itching, tearing, foggy vision, headache, bitter taste, arrhythmia, tiredness and nausea (3,4). However, people with glaucoma living in Sweden generally felt their health-related quality of life was good (7).

There are 5.3 million people in Finland and about 650,000 (12%) of them live in the northern part of the country (8). According to the latest Finnish Register of Visual Impairment, 80,000 people in the country live with visual impairment, 6.4% of which is caused by glaucoma. The prevalence (age- and gender-standardized) for 10,000 people is 33.5. The prevalence is high in the Lapland area (47) as well as in the Oulu UCH area (39.8). In the Helsinki UCH area, the prevalence is 27.7. (9) During 2008, over 76,000 people were entitled to reimbursement for glaucoma medicines in Finland, with 11% of these living in northern Finland (10). In the past, it has been estimated that by the year 2010, there could be 60 million people living with glaucoma, and it could be the second leading cause of blindness worldwide. The number of people with glaucoma in Europe could be 12 million by the year 2010 and 13.9 million by the year 2020 (11).

The problem of getting people with glaucoma to maintain their treatment regimen is common in all parts of Finland, as is also the case in Norway (4). The illness requires patients to regularly visit an ophthalmologist and undergo follow-up inspections. Access to this care may be challenging, especially in northern Finland, where distances are great and the number of ophthalmologists is lower than in southern parts of the country. People have to take responsibility for their own care and follow-up visits. This is why it is very important for people with glaucoma to adhere to their prescribed treatment plans and appointment schedules.

Adherence to glaucoma treatment has been widely studied in medicine (12–25), but these studies have focused only on medication. In reality, patients also must adhere to other health regimens, not just medication. In the field of Nursing Science, adherence has a definition which means more than simply taking prescribed medications, but there are fewer studies that use this approach (5,26). In this study, treatment adherence is defined as a patient's responsible, intentional and active role in self-care to maintain his/her health in collaboration with health care personnel (27). According to previous studies, as many as half of people with glaucoma who use medication do not follow their physician's instructions, and 20% of them do not show up for the follow-up visit (1,28,29). Lunnela, Kyngäs and Hupli (5) point out that 58% of people with

glaucoma adhered well to their care, and 70% adhered well to their medical care. The reason for failure to use eyedrops might be forgetfulness (17), inadequate information or simple the inability to correctly administer the medication (30,31). Typical reasons for not showing up for the follow-up visit are that the patient does not perceive the illness as being that serious and the cost of the examination being too high (20).

Earlier studies (5,32–34) have indicated that the factors connected to treatment adherence include the motivation to take care of oneself, good energy levels, support from physicians, nurses, relatives and friends, a sense of normality, positive consequences from treatments and not fearing complications. In contrast, it is known that lack of motivation and lack of support are connected to poor treatment adherence. In addition, if patients are not aware of the consequences of treatment (or how leaving the disease untreated will affect their quality of life) it can lead to a careless attitude towards self-care and to poor adherence. Ways to improve the motivation of people with glaucoma to adhere to treatment include effective patient education provided by nurses and by devoting adequate time to patient education (26,35,36). People with glaucoma receive education and information from their ophthalmologist (37), from literature and from nurses (5).

The aim of this study was to produce knowledge that could be used to develop effective interventions to improve treatment adherence. The research questions were:

1. How do people with glaucoma adhere to care?
2. Which factors are connected to adherence of people with glaucoma?

## MATERIAL AND METHODS

***Questionnaire***

Because the valid and reliable Adherence Instrument (ACDI), developed and tested by Kyngäs (5,27,38), was available, there was no reason to develop a new questionnaire for this study. For the study, the questionnaire was pretested by people with glaucoma (n=97) to examine its utility. Before pretesting, some modifications were made to the questionnaire to make it more suitable for people with glaucoma; for example, the item concerning support from parents was changed to support from relatives and friends. Because it was likely that some respondents might have impaired vision, a large font size in bold was used (Arial 14), and colours were chosen so that the contrasts were as clear as possible (39). Reliability was evaluated using Cronbach alpha values, which showed reliability ranging from poor to excellent (between 0.04 to 0.85) (5). The lowest Chronbach alpha, 0.04, is poor. That sum variable had only 2 items and the internal consistency of those items was not good.

The final pretested version of the questionnaire consisted of 13 demographic questions and 33 items on the following topics: adherence (medical care, responsibility, care-planning and carrying out care) and factors connected to adherence (support from physicians and nurses, sense of normality, support from relatives and friends, motivation and energy, consequences of treatments and fear of vision loss). The questionnaire was formatted using 5-point Likert scales ranging from strong agreement through indecision to strong disagreement.

***Data collection***

A total of 513 questionnaires were distributed and 262 were returned, the response rate being 51%. However, 13 questionnaires were disqualified because they were inadequately completed. Finally, 249 questionnaires were analysed. The data were collected between July 2006 and October 2007.

A sample of 249 adults with a diagnosis of glaucoma was recruited to participate in this cross-sectional study. These people visited the central hospital outpatient clinic or a private ophthalmologist (a purchased service paid for by the central hospital) in southern Finland. The criteria for inclusion were a minimum age of 18, use of glaucoma medication and capability to answer in Finnish. Long-term hospitalization was an exclusion criterion.

The researcher chose the eligible participants who met the criteria on the basis of referrals. The questionnaire, cover letter and an envelope with the return address were mailed along with the appointment card to the people selected. The subjects mailed the completed questionnaire in a sealed envelope to the IT service provider (a Finnish company specializing in health care quality development), and the provider entered the data into the database. This study was conducted in collaboration with the company in question. The data could only be accessed through hospital computers by the researcher.

***Participants***

The mean age of the participants was 66 years (MD 68, SD 11.9), ranging from 23 to 92 years. Most of participants were female (66%). Thirty-seven percent had had glaucoma for less than 3 years and 32% for more than 9 years. About half (52%) felt that glaucoma adversely effects everyday life. Most participants (97%) received information from their ophthalmologist (Table I).

***Data analysis***

The data were analysed with the Statistical Package for the Social Sciences 15 (SPSS 15) software for Windows. Missing values were replaced

**Table I.** Descriptive statistics for participants (n=249).

| Characteristic | n | n (%) |
|---|---|---|
| Gender | 249 | |
| Female | | 165 (66%) |
| Male | | 84 (34%) |
| Age 249 | | |
| ≤ 61 years | | 84 (34%) |
| 62–73 | | 86 (34%) |
| >73 | | 79 (32%) |
| Duration of illness | 248 | |
| ≤ 3 years | | 91 (37%) |
| 4–9 | | 78 (31%) |
| > 9 | | 79 (32%) |
| Adverse effects on everyday life | 240 | |
| yes | | 126 (52%) |
| no | | 114 (48%) |
| Received information | 249[a] | |
| ophthalmologist | | 241 (97%) |
| nurse | | 35 (14%) |
| optician | | 16 (6%) |
| literature | | 76 (30%) |
| the Internet | | 43 (17%) |
| no information | | 1 (0.4%) |

[a] Respondents were able to choose more than one alternative.

with each item's mean value. In order to verify the construct validity of the questionnaire and format sum variables, factor analysis was carried out. Principal component analysis (PCA) yielded a 10-factor solution. These factors explained 65% of total variance. No items were deleted because communalities in all items were good (>0.30). Three items loaded on 2 factors each and they were placed in most consistent factors. The factor loading of all variables was 0.40 or higher, meaning that the variable will load strongly on a particular factor (40).

Sum variables were formatted based on factor analysis and named according to the contents of factors. Two variables which were not loaded on factors were analysed separately. The sum variables (SUM1–8) had at least 2 items. Factors measuring treatment adherence were named adherence to medical care (SUM5), responsibility (SUM6), care-planning (SUM8) and carrying out the care (variable 3), and a sum variable of good adherence (SUM9) was formed of these factors. Factors measuring connection to adherence were named support from nurses and physicians (SUM1), sense of normality (SUM2), support from relatives and friends (SUM3), motivation and energy (SUM4), consequences of treatments (SUM7) and fear of vision loss (variable 33) (Table II). Sum variables and single variables were categorized into 2 categories based on the assumption of earlier studies (5,38) that when answering "totally agree" (5 points) or "partly agree" (4 points) the respondent was considered to be very adherent.

Factors related to adherence were analysed by cross-tabulating the categorized sum variable good adherence (SUM9) with demographic data and other categorized sum variables (SUM1-8) as well as with 2 single and categorized variables, 3 and 33. In a chi-square test the significance was $p<0.05$ (40,41).

### *Reliability and validity*

The questionnaire was used and tested previously in a pilot study (5). According to these tests, the structural validity and internal consistency were good (38). Before the pretesting of the question-

**Table II.** Cronbach's alpha values related to sum variables of adherence and factors connected to it.

| Sum variable | Number of variables | Cronbach's alpha |
|---|---|---|
| **Sum variables of adherence** | | |
| SUM5 | | |
| Adherence to medical care | 3 | 0.507 |
| SUM6 | | |
| Responsibility | 2 | 0.209 |
| SUM8 | | |
| Care-planning | 3 | 0.379 |
| SUM9 | | |
| Adherence to care | 9 | 0.418 |
| **Sum variables of factors connecting adherence** | | |
| SUM1 | | |
| Support from nurses and physicians | 8 | 0.884 |
| SUM2 | | |
| Sense of normality | 6 | 0.586 |
| SUM3 | | |
| Support from relatives and friends | 3 | 0.795 |
| SUM4 | | |
| Motivation and energy | 4 | 0.625 |
| SUM7 | | |
| Consequences of treatments | 2 | 0.176 |

naire, 10 patients with glaucoma and 4 ophthalmic nurses filled the questionnaire to ensure content validity. Based on the feedback, no changes were made to the questions (5).

Here the construct validity of the questionnaire was tested by PCA, which is generally used to ensure construct validity. PCA produced a factor solution with good statistical values, which was very similar to the earlier studies where the questionnaire was used. Therefore, the construct validity of the questionnaire was high. However, there are some problems with reliability concerning internal consistency, which was evaluated by Cronbach alpha values of each sum variable (Table II). Most of the alpha values were good. Views on the acceptability of alpha coefficients vary. Nunnally (42) considers .60 acceptable for survey research, while DeVellis (43) argues that coefficients below .60 are unacceptable, between .60 and .65 undesirable, between .65 and .70 minimally acceptable, between .70 and .80 respectable and between .80 and .90 very good. Low alpha values indicate that the items in the sum variables SUM6 and SUM7 (both with only 2 items) and SUM8 do not exactly measure the same issue (40,44). Study organizers considered combining these sum variables with other sum variables, but their contents did not match. Factor loadings of those items were also high, indicating that they belonged to sum variables 6 to 8.

***Ethical considerations***

Permission to carry out this study was granted by the hospital director and the Ethics Committee for Gynaecology and Obstetrics, Otology, Ophthalmology, Neurology and Neurosurgery. The principles of the Helsinki Declaration were followed (45). Subjects were given a cover letter stating the aim of the study. They were also informed that participation was voluntary and that either taking part in the study or choosing not to would have no impact on their treatment. Answering the questionnaire was considered a voluntary consent. Issues of confidentiality were taken into account at the hospital, resulting in a database that could only be accessed by the researcher. The results of the study have been reported honestly. The research material will be obtained, used and stored according to the authors' host university information management regulations. Regulations will be adhered to and all data collected from participants will be stored, used and destroyed according to regulations.

## RESULTS

***Adherence of people with glaucoma***

Almost all 242 (97%) respondents showed good adherence to medical care (SUM5), while only 3% (n=7) showed poor adherence to medical care. Nearly all (91%, n=226) showed good responsibility in their self-care (SUM6). Only 26% (n=66) of those with glaucoma made plans (SUM8) for their self-care. More than half (59%, n=148) carried out their care in spite of the side effects of eye medication. Sixty-seven percent (67%, n=166) of patients with glaucoma showed good adherence to care (Table III).

***Factors connected to adherence***

More than half of the women with glaucoma adhered well to treatment (69%, n=114), as did 62% of men (n=52). Most patients with glaucoma who adhered well were found in the 62–73 year-old age group (74%, n=64), while those with the poorest adherence (41%, n=34) were seen in the youngest age group (≤61 years). More than half of the very adherent people with glaucoma (66%, n=83) expressed their own feelings of the disease having an adverse effect on everyday life.

However, almost as many very adherent people with glaucoma did not experience adverse effects in everyday life (67%, n=76). Those who had had the illness for 4–9 years were the most adherent to treatment (69%, n=54), while those who had had the illness for more than 9 years (37%, n=29) showed the poorest adherence. Sixty-six percent (66%, n=163) of people with glaucoma who had received information from physicians and nurses were very adherent. Very adherent people with glaucoma had also received information from other sources (69%, n=81), such as opticians, leaflets, literature and the Internet. There was no statistically significant connection between

**Table III.** Adherence of people with glaucoma.

| | **Total** n | **Good adherence** n (%) | **Poor adherence** n (%) |
|---|---|---|---|
| Adherence to medical care SUM5 | 249 | 242 (97 %) | 7 (3 %) |
| Responsibility SUM6 | 249 | 226 (91 %) | 23 (9 %) |
| Care-planning SUM8 | 249 | 66 (26 %) | 183 (74 %) |
| Carrying out the care Variable 3 | 249 | 148 (59 %) | 101 (41 %) |
| Adherence to care SUM9 | 249 | 166 (67 %) | 83 (33 %) |

**Table IV.** Factors connected to adherence of care.

| | **Total** (n= 249) n | **Adherent** (n= 166) n (% of total) | **Poorly adherent** (n= 83) n (% of total) | **p** ($x^2$) |
|---|---|---|---|---|
| **Demographic factors** | | | | |
| Gender | | | | |
| Women | 165 | 114 (69) | 51 (31) | 0.160 |
| Men | 84 | 52 (62) | 32 (38) | |
| Age | | | | |
| ≤ 61 | 84 | 50 (59) | 34 (41) | |
| 62–73 | 86 | 64 (74) | 22 (26) | 0.118 |
| > 73 | 79 | 52 (66) | 27 (34) | |
| Adverse effects on everyday life | | | | |
| high | 126 | 83 (66) | 43 (34) | 0.503 |
| low | 114 | 76 (67) | 38 (33) | |
| Duration of illness (years) | | | | |
| ≤ 3 | 91 | 61 (67) | 30 (33) | |
| 4–9 | 78 | 54 (69) | 24 (31) | 0.727 |
| > 9 | 79 | 50 (63) | 29 (37) | |
| Information source | | | | |
| Physician or nurse | 246 | 163 (66) | 83 (34) | 0.295 |
| Other sources | 117 | 81 (69) | 36 (31) | 0.251 |
| **Factors connected to adherence of care** | | | | |
| Support from nurses and physicians (SUM1) | 249 | 126 (51) | 123 (49) | <0.001 |
| Sense of normality (SUM2) | 249 | 154 (62) | 95 (38) | 0.712 |
| Support from relatives and friends (SUM3) | 249 | 150 (60) | 99 (40) | 0.170 |
| Motivation and energy (SUM4) | 249 | 230 (92) | 19 (8) | 0.177 |
| Consequences of treatments (SUM7) | 249 | 217 (87) | 32 (13) | 0.003 |
| Fear of vision loss | | | | |
| afraid | 226 | 152 (67) | 74 (33) | 0.536 |
| not afraid | 23 | 14 (61) | 9 (39) | |

background variables and the factors connected to adherence.

Half of the people with glaucoma who adhered well to treatment (51%, n=126) had received support from physicians and nurses (SUM1). Support from physicians and nurses had a statistically significant connection to treatment adherence ($p<0.001$); more than half (60%, n=99) of those who had received insufficient support were adhered well, while 67% (n=56) of those who had received little support adhered poorly. A sense of normality (SUM2) was typical among people with glaucoma who adhered well (62%, n=154), as was support from relatives and friends (SUM3, 60%, n=150). However, SUM2 ($p=0.712$) and SUM3 ($p=0.170$) did not have a statistically significant connection to adherence.

Very adherent people with glaucoma were very motivated and felt that they had an abundance of energy (92%, n=230). However, only 8% (n=19) of poorly adherent people with glaucoma felt they had enough motivation and energy (SUM4, $p=0.177$). Many very adherent people with glaucoma experienced positive results from treatments. Results from treatments had a connection to adherence; 87% (n=217) of very adherent people with glaucoma experienced good results from treatments. Only 13% (n=32) of the poorly adherent people with glaucoma experienced positive results from treatments (SUM7, $p=0.003$).

Fear of vision loss was very common among people with glaucoma. Almost all (91%, n=226) were afraid of losing their vision. However, fear of vision loss had no statistically significant connection to adherence since 67% (n=152) of very adherent people with glaucoma feared losing their vision because of the illness, while 33% (n=74) of the poorly adherent were also afraid of losing their vision (variable 33, $p=0.536$).

## DISCUSSION

These results illustrate that two-thirds of people with glaucoma adhere well to their treatment plans. According to previous studies, only about half of people show good adherence to treatment plans (1,5,28,29), so it seems that people with glaucoma adhere better than people with other chronic diseases. Additionally, people in this study were more adherent to medical care than in a previous study (5). This is remarkable, because one of the most important aspects of glaucoma management is regular eyedrop administration (2). However, it is essential to consider whether respondents answered the items on medication honestly or whether they responded in the way they knew they should. Regardless, most patients had fears of vision loss, and this may have been sufficient motivation to use eyedrops as recommended. People with glaucoma have reported that the illness has adverse effects on their lives (4), but also opposite findings have been demonstrated (7). In this study most of the glaucoma patients were afraid of vision loss as was also indicated by Odberg (4). This illustrates the fact that they were quite well aware of the functional and structural abnormalities caused by glaucoma (1).

Based on earlier studies, it is known that motivation is a very important factor connected to good adherence to a treatment plan (5,32–34). This result was not as clearly indicated in the present study. However, people with glaucoma appeared to be responsible and well motivated to take care of themselves, they were relatively active and their collaboration with health care personnel was good, as also indicated by previous studies (5,32–34). Arguably, patients are unable to assume full responsibility for their care if they do not have the necessary knowledge and skills as well as the requisite mental readiness. In light of this,

patient support and education is very important for improving patients' adherence to their health regimens and their willingness to assume responsibility for that care (26,35,36).

Patients expect to get support from health care providers. According to this study, more than half of those who had received support and patient education adhered well to their treatment plans, and correspondingly, more than half of those who had not received support or patient education were poorly adherent. Based on this finding, it can be concluded that receiving proper information and patient education leads to better treatment adherence. This is also supported by earlier studies (26,32,33,35,36). However, this is a big challenge for doctors and specialists in northern Finland as well as in other sparsely populated areas. In Lapland in northern Finland, the need for patient education is high because of the high prevalence of glaucoma. Despite this, the number of ophthalmologists is lower than those residing in southern Finland. In addition, northern Finland is very sparsely populated. Only 3.5% of the Finnish population live there, and the average population density is 2 people per square kilometre. These conditions pose a challenge to providing adequate patient education and support. Computer-based interventions may help, but there have been contradicting findings as to whether these are effective or not.

Knowledge of consequences of treatment had a statistically significant connection to treatment adherence. This is supported by earlier studies (5,32–34). If patients are made well aware of the consequences of treatments (or the lack of treatment), they know why they have to follow the instructions given by health care providers. In that case, their actions are reasonable and lead to positive effects. It is necessary for them to know both why and how they have to follow the instructions provided. They also need to have the proper skills to carry out treatments (5,32).

There are some limitations in this research. First, the response rate was only 51%. This is better than the usual response rate for mailed questionnaires (25–30%) (41); nevertheless, the low response rate might indicate poor treatment adherence among people with glaucoma, since poorly adherent people do not answer questionnaires of this kind. When studying treatment adherence, it is essential to recognize that subjects are giving their own estimate of their adherence, which may not be an accurate reflection of reality. However, there is no other way to measure treatment adherence. According to earlier studies (5,38), poorly adherent people give a better impression of their adherence than what is actually the case. It was mentioned in the cover letter that there are no right or wrong answers and that respondents are supposed to answer according to the way things are in their lives, not as they would like them to be. This statement might lead people to provide answers that they think are "good" or "appropriate" instead of accurate. However, these results support the earlier findings of the pilot study by Lunnela et al. (5), so it can be concluded that the results of this study are valid.

Second, in terms of technical implementation, the possible vision loss of respondents was taken into consideration by using a large and clear font and good contrast in the questionnaire (39). However, the instructions in the cover letter were not clear enough and that might have decreased the validity. This weakness was indicated in many items that were not answered, although indecision was also a possible reason for unanswered items.

Third, the support from relatives and friends was crucial for treatment adherence because almost two-thirds of those who had received support from relatives and friends showed good

adherence. As most of the respondents were elderly (MD 68 years), it can be considered that many elderly people may receive support from their relatives for other reasons as well, such as for other illnesses (30,31). Indications of this did not appear in the study, because the respondents were not asked about other illnesses. When studying elderly people it is perhaps more reasonable to examine their life situations in a holistic way, taking other illnesses and the surrounding environment into consideration. However, it can be concluded that the respondents were in relatively good health, because no long-term hospitalized respondents were included in this study.

Fourth, this study was conducted in southern Finland. The prevalence of glaucoma is higher in northern Finland (Lapland has an average of 47), where it is more difficult to visit an ophthalmologist because of the great distances patients are required to travel. It would be very important to study if those great distances are connected to adherence of people with glaucoma living there. Adherence of people with glaucoma has not been studied much in other Nordic countries. It would be interesting to investigate and compare people living in those areas. As well, there are no studies concerning the role of telemedicine in glaucoma treatment. That would also be a very interesting subject to study.

In summary, these results indicate that nurses and physicians play a very important role in providing patient education and support. In practice, it is crucial to at least maintain this level of access to information by developing more tailored and time-saving education and support methods. It is even more important to identify poorly adherent patients with glaucoma as early as possible to increase their adherence not only to properly taking their medication but also to follow-up visits and self-care. However, a more holistic attitude that involves discussing patients' care with them and including them in the decision-making process is required from health care personnel. The findings of this study are useful in developing patient education and support methods for people with glaucoma.

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